

Diagnosis and Treatment

60. What are the symptoms of HIV infection?

Shortly after being infected with HIV, some people – but not all people – have flu-like symptoms (fever, muscle aches, feeling tired) that last a few days and then go away. This is sometimes called *seroconversion illness* or *acute HIV infection*. Most people with HIV have no symptoms for many years. However, even without symptoms, people who are newly infected have large amounts of HIV circulating in their blood and are highly infectious at that time.

HIV infection **cannot** be diagnosed from symptoms alone. The symptoms of worsening HIV infection and AIDS – swollen glands, fever, and skin rashes – can also be caused by other illnesses, many of which are more common than HIV infection. Only an HIV test can show whether a person has HIV (see Testing section, page 15).

61. When does a person with HIV infection have AIDS?

According to the Centers for Disease Control and Prevention (CDC), a person with HIV infection has AIDS when:

- the person's CD4 cell count, a way to measure the strength of the immune system, falls below 200 (a normal CD4 cell count is 500 or higher); or
- the person develops any of the specific serious conditions – also called AIDS-defining illnesses – linked with HIV infection (see Appendix for a list of these conditions).

62. Why is it important for people with HIV to get medical care?

People with HIV should seek early medical care so they can:

- find out about medicines that fight HIV; and
- receive care for HIV-related conditions.

Treatments that fight HIV help people with HIV live longer, healthier lives. Often, it is best to start treatment before symptoms appear. A doctor can do blood tests to find out how much HIV is in a person's body and how much damage the virus has done to the immune system. This information helps people with HIV and their doctors decide when to start treatment and how well treatment is working. Early medical care helps people with HIV take best advantage of treatments for HIV.

Certain medicines can also prevent some opportunistic illnesses like PCP (*Pneumocystis carinii* pneumonia). Testing and treatment for other illnesses, like TB (tuberculosis) and STDs (sexually transmitted diseases), is also important. These illnesses are more common in people with HIV and can make HIV progress more quickly to AIDS.

It is important to see a doctor who is well informed about HIV. The New York State Department of Health designates doctors who meet certain criteria, like treating HIV-infected patients and taking special courses in HIV-related topics, as HIV specialists.

63. Do women with HIV need special medical care?

Yes. Some medical problems are more common in women with HIV. These include:

- Cervical cancer. HIV-infected women also have high rates of HPV (*human papillomavirus*) infection, especially those types that lead to the development of cervical cancer. Treatment with antiretroviral drugs may be able to change the course of HPV infection, but this has not yet been proven.
- Vaginal yeast infections, which may be more frequent and need longer treatment in women with HIV.

Women with HIV should have yearly pelvic exams and PAP smears to look for cervical cancer. Women with HIV also need to know how to prevent pregnancy (if they do not wish to become pregnant) and how to prevent passing HIV to their babies if they do choose to get pregnant. They should talk to a doctor about family planning, including how birth control pills interact with some HIV medicines.

It is especially important for pregnant women with HIV to get medical care, because there are medicines that women with HIV can take to greatly reduce the risk of their babies being born with HIV. Children with HIV infection also need medical care as early as possible.

64. Should people with HIV tell their doctor, dentist, physician assistant, nurse practitioner, and other health care providers?

Yes. To provide the best medical care, health care providers need to know the HIV status of their patients. It is against the law for health care providers to deny care to people with HIV because of their HIV status. By law, health care providers *must* keep your HIV status confidential (see question 94).

65. What are CD4 cell counts and viral load tests?

CD4 cells are part of the immune system. Over time, HIV kills CD4 cells, making the immune system weaker. A person's CD4 cell count shows the strength or weakness of the immune system.

Viral load is the amount of HIV in a person's blood. Over time, without treatment, the viral load of a person living with HIV gets higher. HIV treatment with HAART (Highly Active Anti-Retroviral Therapy) usually lowers the viral load. When the amount of HIV in the blood is so low that blood tests cannot find it, it is called an *undetectable* viral load. A person with an undetectable viral load is less likely to get sick but still has HIV and can pass the virus to others.

CD4 cell count tests and viral load tests give people with HIV and their doctors important information about a person's HIV infection and immune system strength. These tests help show whether a person should consider taking medicines for opportunistic infections and/or medicines to fight HIV (HAART). They also show how well HAART is working. People with HIV should have a CD4 cell count test and a viral load test done at least every six months. If they are taking HAART, these tests should be done at least every four months.

New York State laboratories automatically give the results of these tests and drug resistance tests to the State Department of Health (see questions 67 and 88). The reporting process is very secure and confidential. Getting these test results will help the State Department of Health track the quality of health care for people with HIV; find out about drug-resistant strains of HIV in the community; and better track the epidemic to plan prevention, health care, and support services.

66. How is HIV infection treated?

Treatment for HIV infection includes:

- Highly Active Anti-Retroviral Treatment (HAART);
- preventive treatment to avoid opportunistic infections;
- treatments for HIV-related illnesses; and
- healthy living practices.

HAART. HAART (Highly Active Anti-Retroviral Therapy) involves taking three or more drugs that fight HIV at the same time. HAART can strengthen the immune system and reduce the amount of HIV in the blood.

Many medicines are available, and no one combination is best for everyone. Not everyone with HIV needs HAART, which is usually started only when signs of immune system damage or symptoms of HIV appear (see question 68).

Drugs that fight HIV are divided into several “classes” or types. The different classes of drugs are used in combinations. Each class of drugs affects HIV in a different way:

- **NRTIs** (nucleoside and nucleotide reverse transcriptase inhibitors) interrupt the first step that HIV takes to “copy” itself inside a cell.
- **NNRTIs** (non-nucleoside reverse transcriptase inhibitors) also interrupt the first step that HIV takes to copy itself, but in a different way than NRTIs.
- **Protease inhibitors** interrupt the last step that HIV takes to copy itself.
- **Entry inhibitors** (including **fusion inhibitors**) stop HIV from entering a healthy cell.

New medicines in each of these drug classes are being developed. New drug classes, which attack HIV in new ways, are also being researched.

Drugs that fight HIV have improved the health of many people, but these treatments are not perfect. HIV medicines can be hard to take and often have side effects, some of which are serious and even life threatening. Missing or delaying just a few doses of medicine can lead to the person developing “resistance” to the drugs, which means that the drugs will stop working (see question 67).

Preventive medicines. Opportunistic illnesses like PCP (*Pneumocystis carinii* pneumonia) and MAC (*Mycobacterium avium* complex) affect people whose immune systems are severely weakened by HIV. However, many of these illnesses can be prevented by taking certain medicines as soon as the immune system becomes weak. Since the immune system can be severely weakened before symptoms appear, it is

HAART can strengthen the immune system and reduce the amount of HIV in the blood.

important for people with HIV to see their doctors so that they can begin preventive treatment as soon as it is needed. A HAART regimen is the most effective way to strengthen the immune system.

Treatments for AIDS-related illnesses. Treatments for AIDS-related cancers, infections, and other conditions are available. Combining these treatments with HAART, as needed, can help people with AIDS live healthier, longer lives.

People with HIV should ask their doctor, nurse, or case manager for more information about these topics before they make any changes to their treatment plan.

Healthy living. Good health habits can play an important role in the treatment of HIV. Important factors include:

- eating healthy foods
- preparing and storing food safely
- taking vitamins as directed by a doctor or nutritionist
- exercise (both aerobic and muscle-building)
- getting enough sleep
- stress management
- avoiding alcohol, cigarettes, street drugs, and other harmful substances. Smoking increases the risk of bacterial pneumonia, thrush, and other oral health problems.

67. What is drug resistance?

Drug resistance happens when HIV *mutates*, or changes itself, so that the HIV medicines a person is taking are no longer effective. People who become resistant to one drug may also become resistant to other drugs, including drugs they have never taken. Tests are available to help find out whether a person is resistant to any HIV medicine.

Drug resistance is much less likely to develop if the amount of HIV in a person's body is kept as low as possible. That is why it is important that people with HIV take their HIV medicines as prescribed and not skip doses. Case managers, adherence counselors, and treatment educators can help people with HIV figure out strategies for taking their HIV medicines successfully (see questions 65 and 88).

68. When should a person with HIV begin taking HIV medicines?

There is no one simple answer to this question. Many factors influence the decision to begin taking HIV medicines, including CD4 cell count, viral load, symptoms, concern about side effects and your ability to deal with them, and your ability to take the medicines correctly. The following recommendations are based on CD4 count, viral load, and symptoms, but people with HIV should keep in mind that personal factors are important, too.

Treatment is strongly recommended if:

- symptoms of HIV/AIDS appear; or,
- CD4 count falls below 200.

Treatment should be offered if:

- there are no symptoms, but CD4 count is between 200 and 350; or,
- there are no symptoms, and CD4 count is higher than 350, but viral load is higher than 55,000 copies/mL PCR. Some experts would delay treatment at this point, but would keep checking viral load and CD4 cell counts.

Treatment is not recommended if:

- CD4 count is higher than 350, viral load is less than 55,000 copies/ mL PCR, and there are no symptoms of HIV/AIDS. Most experts would not begin treatment and would continue checking viral load and CD4 cell counts.

69. Can a person who is on methadone maintenance take HIV medicines?

Yes. However, some HIV medicines interact with methadone and may require a change in the dosage of methadone or the HIV medicine. People with HIV should tell their doctors about all the medicines they take, including methadone, so that their doctors can prescribe medicines that will work best. People on methadone should tell their methadone clinic about any HIV medicines they take so that they can get the dose of methadone they need.

70. Are there alternative or complementary treatments for HIV?

Many people with HIV are interested in alternative or complementary treatments, including herbs, supplements, acupuncture, and other nontraditional treatments. Some people feel that these treatments reduce their symptoms, such as nausea or pain. Unfortunately, the safety and effectiveness of many of these treatments have not been well studied or are not known. In some cases, these treatments may be harmful. Some commonly used supplements, including St. John's Wort and milk thistle, have been shown to reduce the effectiveness or increase the side effects of some HIV medicines.

To avoid problems, people with HIV should tell their doctors about all of the treatments they use, including all herbs, vitamins, and other supplements.

71. What is the connection between HIV and TB?

TB (tuberculosis) is one of many diseases that a healthy immune system can usually keep under control. Only about 10% of people with normal immune systems who have the TB bacteria will get sick with active TB.

However, a person with HIV who has the TB bacteria and a weak immune system is much more likely to develop active TB disease. Untreated active TB can be spread to others by coughing. TB can usually be cured with medicines. Active TB can be prevented by taking medicine before symptoms start. All people with HIV who have not had a positive TB skin test in the past should be tested for TB once a year. That way, if they are infected, they can take medicine to avoid getting sick with active TB.

72. What do people with HIV need to know about hepatitis?

People with HIV should be tested for hepatitis A, hepatitis B, and hepatitis C. These illnesses can cause severe liver problems, especially in people with HIV. Hepatitis A is commonly spread through contaminated food or water. Hepatitis B and hepatitis C can be spread through unprotected sex or by sharing needles with a person who has either of these viruses. People with HIV should talk to their doctor about their risk for hepatitis, how to avoid infection, and whether they should receive vaccines to prevent hepatitis A and hepatitis B (there is no vaccine for hepatitis C). There are treatments available for hepatitis B and hepatitis C, but they do not work for everyone.

73. Where can people with HIV get medical care?

Hospital clinics. The New York State Department of Health has identified some hospitals as Designated AIDS Centers because they have special care programs for people with HIV infection and AIDS. Designated AIDS Centers are required to coordinate the full range of medical services needed by patients with HIV and AIDS, including inpatient and outpatient care, home health care, oral health care, and mental health care. Some Designated AIDS Centers now have special programs for women, children, and adolescents with HIV and AIDS. These hospitals are also generally involved in HIV-related research programs. There are also hospitals that are not Designated AIDS Centers but have experience in treating people with HIV. For more information about Designated AIDS Centers, call the New York State Department of Health AIDS Institute HIV Health Care Section at (518) 486-1383.

Community health centers. Many people with HIV receive their medical care from clinics in the community where they live. There are also special programs for children, adolescents, and substance users. Most HIV clinics also provide case management to help people with HIV get the other services they need. People who need referrals to health care facilities should contact their nearest AIDS service organization or the HIV Counseling and Testing Hotline: 1-800-872-2777.

Drug treatment programs. For people with HIV who are being treated for drug use, some drug treatment programs also provide HIV medical care on site. To find one of these sites near you, call 1-800-541-AIDS and ask for a listing of drug treatment programs that also have HIV medical care services. This call is free and private. Health care in these sites can be accessed by persons enrolled in the drug treatment program.

Private doctors' offices. People with HIV can get care from private doctors in their community. It is important to see a doctor who is knowledgeable about HIV, sometimes called an *HIV specialist*. Doctors who take special training and meet certain requirements are called HIV specialists by the New York State Department of Health.

Day treatment programs. There are many adult day treatment programs in New York State that offer medical care, nursing care, and substance use and related health services to people with HIV who meet certain requirements. For more information, call the New York State Department of Health AIDS Institute Chronic Care Section at (518) 474-8162.

Home care programs. Throughout the state, a number of AIDS home care programs provide nursing and other services in the homes of people who have AIDS-related illnesses. For more information, call the New York State Department of Health AIDS Institute Chronic Care Section at (518) 474-8162.

Skilled nursing facilities. The New York State Department of Health has helped to develop HIV/AIDS nursing homes that provide medical care and special services for severely ill patients. For more information about skilled nursing facilities, call the New York State Department of Health AIDS Institute Chronic Care Section at (518) 474-8162.

74. How can people with HIV and AIDS pay for their medical care?

Care for patients with HIV infection and AIDS is generally paid for in the same way as other forms of medical care:

- by the government (Medicaid, Medicare, and the HIV Uninsured Care Program, which includes the AIDS Drug Assistance Program, known as ADAP); or
- by private insurance companies.

Most group health insurance plans cover HIV and AIDS medical treatment, although some have a maximum amount they will cover. People with HIV who are on Medicaid can now choose an HIV Special Needs Plan (SNP). SNPs are special Medicaid Managed Care Plans that allow people with HIV to choose HIV specialists as their primary care doctors and give patients access to special services (see question 75).

The New York State Medicaid Program pays for drugs for persons on Medicaid. In addition, the New York State Department of Health operates the HIV Uninsured Care Program, including ADAP, which offers free drugs, primary care, and home care for people who do not qualify for Medicaid and who meet income requirements. ADAP can help people with no insurance or partial insurance. The program includes these services:

- ADAP pays for medicines for the treatment of HIV- and AIDS-related conditions.
- ADAP Plus (Primary Care) pays for primary care services at participating clinics and hospital outpatient programs, drug treatment programs, and private doctors' offices.
- The HIV Home Care Program pays for a person's home care services that are identified by their doctor. The maximum lifetime Home Care benefit per person is \$30,000.
- APIC (ADAP Plus Insurance Continuation) pays for the health insurance of people with HIV who meet certain income and insurance criteria.
- AHIP (AIDS Health Insurance Program), operated by Medicaid, also pays for the health insurance of people with HIV who meet certain employment, income, and insurance criteria. But the criteria are slightly different from those of the APIC program. People who do not qualify for AHIP may qualify for APIC.

SNPs are special Medicaid Managed Care Plans that allow people with HIV to choose HIV specialists as their primary care doctors and give patients access to special services.

For more information about the HIV Uninsured Care Program, call 1-800-542-2497 or (518) 459-0121 for TDD.

75. Are people with HIV who receive Medicaid required to join a managed care program?

No. People with HIV/AIDS who are on Medicaid do not have to join a managed care plan and can continue to get health care as they have in the past. However, this may change in the future, and people with HIV/AIDS who are on Medicaid may have to choose between a regular managed care plan or an HIV Special Needs Plan (SNP).

SNPs are special health care plans for people with HIV or AIDS who are on Medicaid. People who join an HIV SNP choose a primary care doctor who is an HIV specialist – a doctor with special training and experience in treating people with HIV. SNPs pay for the same services as regular Medicaid, plus special services that are important for people living with HIV/AIDS.

For more information about SNPs and managed care choices for people receiving Medicaid, call the New York Medicaid CHOICE HelpLine at 1-800-505-5678 or 1-888-329-1541 TTY/TDD.

76. Do prisoners have access to up-to-date HIV treatments?

All people with HIV, including those in prison, should have access to health care and appropriate HIV treatment. For more information, speak with the medical staff at the prison or contact the New York State Prison HIV Hotline at (716) 854-5469, Monday - Friday, 12-8pm; Saturday - Sunday, 10am-6pm; collect calls are accepted from inmates in NYS correctional facilities.

77. How can I learn about experimental treatments for people with HIV?

For information about clinical trials or experimental treatments for HIV in New York State and nearby areas, contact the AIDS Community Research Initiative of America (ACRIA). ACRIA can help locate a specific clinical trial and provide treatment education and information on community services. For more information, contact ACRIA at (212) 924-3934, ext. 121 or by e-mail: treatmented@acria.org. The group's website address is: www.acria.org.

ACRIA provides detailed information on many federally and privately sponsored clinical trials. Call 1-800-TRIALS-A.